

Organ procurement: let's presume consent



Education

Éducation

Fady Moustarah, MD

In brief

IN WINNING FIRST PRIZE in the Logie Medical Ethics Essay Contest in 1997, Dr. Fady Moustarah made a strong and compelling argument in favour of presumed consent in the procurement of donor organs. He stressed that a major education campaign will be needed when such a policy is adopted lest some people begin to regard physicians as "organ vultures."

En bref

DANS LE TEXTE QUI LUI A MÉRITÉ LE PRIX LOGIE de dissertation en éthique médicale de 1997, le Dr Fady Moustarah présente de solides arguments en faveur du consentement présumé pour prélever des organes d'un donneur. Il souligne aussi qu'il faudra une grande campagne d'éducation publique lorsqu'une telle politique sera adoptée, sans quoi certains pourraient percevoir les médecins comme des «prédateurs d'organes».

Transplants involving cadaver organs are among contemporary medicine's greatest success stories because they mean an increased survival rate and better quality of life for people with end-stage organ failure (ESOF).

As well, "there is every expectation that [transplant results] will continue to improve in the future."¹ Unfortunately, demand for organs far outstrips supply and the rationing that results essentially condemns many patients to death. Medicine could, and should, move in a direction that would alleviate the need for these rationing decisions.

Saving life is a core moral principle in medicine; in fact, the principle of beneficence holds that physicians ought to find ways either to save the lives or to improve the quality of life of their ESOF patients. It is ethically unacceptable to ignore the plight of patients who could be saved.

Allocating life and death

How can we avoid allocation decisions and save the lives of those on transplantation waiting lists? Although several factors are involved, the major limiting factor in Canada is the inadequate supply of donor organs.² This puts our line of attack in clear focus.

Canada currently has an opting-in policy, which means that organs are harvested only if someone has provided consent, and this system fails to meet the growing need. We must adopt a better procurement policy. In Alberta there have been suggestions to switch to an "opting-out" policy, a practice often referred to as "presumed consent." Although the idea has been floated within the transplantation field since 1968,³ it has not gained widespread support and governments have been reluctant to adopt it. Physicians might assume that this reluctance means the practice is morally objectionable, but they shouldn't be misled. A system of presumed consent not only will increase the organ supply but is also

Dr. Moustarah, a 1997 graduate of the University of Alberta, is in his PGY-1 year in general surgery in the Department of Surgery at McMaster University.

Can Med Assoc J 1998;158:231-4



morally defensible because it better respects the individual autonomy that the current opting-in system strives so hard to protect.

Supply and demand

One author noted that “figures need not be invoked to remind us that we face a donor organ shortage.”⁴ Although I will rely on “figures,” I will also emphasize that behind every one of them is a man, woman or child whose life is in jeopardy and can potentially be saved. In the US, for example, “there has been a 12.4% increase in the need for kidney, heart, liver, heart-lung and pancreas transplantation procedures between 1980 and 1990.”⁵ During this period the need for cadaver kidneys increased by 267%. In June 1991 more than 23 000 people were on the United Network for Organ Sharing waiting list — a 75% increase since 1987. Unfortunately, the supply of donor organs has remained relatively unchanged since 1980.

Canada is witnessing similar trends. Of the 1067 patients awaiting kidney transplantation in Alberta in 1990, only 551 underwent the procedure; among patients receiving dialysis in northern Alberta in 1992, half were on a transplant waiting list.²

Our failure to seek an ethical alternative to the organ shortage passes a death sentence on many Canadians and a properly enforced system of presumed consent may help solve the problem. Studies from Belgium and Austria have shown that “the problem of chronic organ shortage can adequately be solved” with an opting-out system⁶ and that there are “enough organ donors for all patients on the waiting list, at least for kidneys.”⁷ Thus, unless it can be proved that presumed consent is ethically unacceptable, we have a duty to pursue this option.

Autonomy and presumed consent

Respect for autonomy requires that we recognize that rational beings have inherent worth and their actions must result from their own deliberations. In Kantian terms, individuals should not be treated as means to an end because of their inherent value. From an ethical perspective, people should have authority over their own bodies; recognizing that saving the lives of ESOF patients is a desirable end does not by itself justify the removal of

organs without prior consent. David Peters concluded that a person is considered to have “a legitimate and primary proprietary in his or her living or dead body” and thus “has first right to control what happens to his or her body before and after death.”⁸ So, how can we best realize the autonomous wishes of people concerning the disposition of their organs?

The Human Tissue and Gift Act (HTGA) of 1971 was adopted by all provinces to ensure that people had authority over their own bodies while also providing an opting-in system to encourage organ procurement. It states

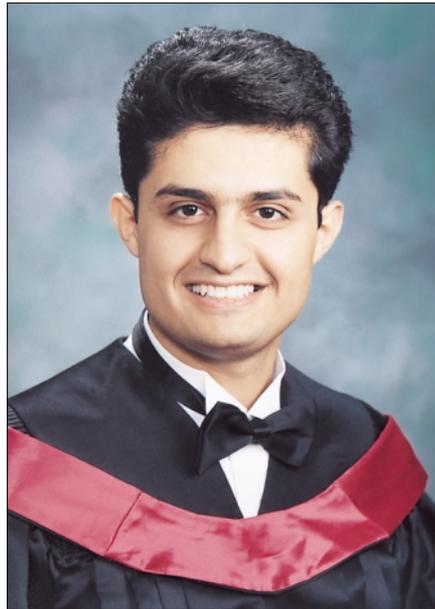
that cadaver organs can only be harvested if the donor has left explicit official consent, which is “binding and full authority for the . . . removal and use of the specified body parts.” The only exception arises when a procurer “has actual knowledge of an objection thereto by . . . a person of the same or closer relationship to the person in respect of whom the consent was given.”⁹ In theory, the HTGA protects donor autonomy while presuming that only those who signed cards want to donate organs.

Such a presumption errs in its empiric foundation: most people who eagerly support organ donation and would also choose to receive a transplant have never signed their donor cards. Studies completed in Ontario and Alberta in 1985 showed that even though there was strong support for organ donation, “70% of individuals had not signed their donor cards.”²

A 1992 study in Alberta found that 77% of respondents would like unlimited access to transplants yet “the percentage of unsigned donor cards has remained relatively constant.”²

It appears that many people who support organ donation have difficulty envisioning their own deaths and find it hard to contemplate donating their organs, although other factors may be in play as well.¹⁰ If asked, many people who fail to sign donor cards would say that organ donations is desirable and noble. Therefore, we err when we assume that the absence of expressed consent implies a refusal to donate. Alternatively, *presuming* consent allows us to meet better the wishes of most people. Hence, presuming that the majority favour organ donation is the morally correct way to proceed because it finds its roots in the recognition of the *unexpressed* but autonomous will of most members of society.

I hesitate to say *unexpressed* autonomous will because with time a properly implemented policy of opting-out



Dr. Fady Moustarah: presume there’s consent, and save lives



can effectively equate the failure to indicate refusal to donate with the indirect expression of consent. In other words, it would be safe to assume that people who have not registered an objection want to donate their organs. To avoid misinterpretation, massive amounts of public education would be needed before any shift to presumed consent. Debates and educational campaigns could be used to raise awareness of the need for organs, the success of transplants, medical criteria for death and the compatibility of organ donation and religious belief. In Singapore, where presumed consent has been the rule since 1987, all residents receive a letter upon attaining the age of majority. It states that they are presumed to consent to organ donation if they do not explicitly object to it; Muslims are considered objectors unless they opt in.¹¹ For minors and mentally incompetent people, consent is sought from next of kin. With measures such as these, everyone should be able to make an informed decision.

Autonomy and next of kin

Besides failing to recognize the wishes of the majority, the current opting-in system violates individual autonomy on another level. Because of exceptions to the “consent is full authority” clause mentioned earlier, the HTGA means decisions are often made by relatives of the deceased. People who procure organs continue to seek permission from next of kin even though consent has already been given. This begs the question of whose rights and autonomy ought to be respected, those of the donor or those of the next of kin?

We make a huge moral mistake when we let the wishes of the next of kin take priority. Seeking such consent is also time consuming and often results in family distress when feelings of guilt and sorrow are prevalent. The time lost may result in tissue death and concomitant organ damage, and even lead to an objection to removal of an organ the deceased person had agreed to donate. The potential consequence is the loss of one more life.

Under our current system, there is little incentive for anyone to sign a donor card. As a potential donor I have to foresee my death, realize the need for organs and sign my donor card as a goodwill gesture, all the time realizing that my family’s wishes might be given precedence over mine. The fact that these wishes often coincide is irrelevant. If I decide to object to organ donation and refrain from signing my card, my wishes may still be overlooked because families can give postmortem anatomical gifts upon request. It is difficult to distinguish between objectors and supporters of organ donation because even though no objectors sign their donor cards, not every person who fails to sign a card is an objector.

A policy of presumed consent can protect the wishes of

objectors because their registered objections would not be subject to contravention. If they change their mind, the burden of cancelling their objection would be on them. As to those who choose not to object, a system of presumed consent allows for rapid removal of organs and meets the medical need for harvesting well-oxygenated tissue that improves the operation’s success rate. By presuming consent, procurers would also be saving families unnecessary grief — they would no longer be asking questions at the worst possible time, questions that should not be asked in the first place.

Technical objections

Despite its appeal as an ethically acceptable method for procuring organs, a presumed-consent policy may face practical difficulties. However, solutions exist.

- Some say that an opting-out registry would become too complicated and would not be able to maintain uniformity across jurisdictional boundaries.^{12,13} This may have been true in the past, but technology and rapid communication mean that we can surely create a system to ensure that objectors can leave directives of their intentions, which would be readily available from a central registry. Also, objectors can still be protected even if we rely on the card system currently in use. Solutions are readily available in Austria, Belgium, Singapore and several other countries with presumed-consent legislation.
- Others argue that presumed consent will lead to distrust of the medical profession because physicians might confuse their role of saving the lives of potential donors with that of harvesting their organs, and may ease off on attempts to help a potential donor. This is simply an argument used by those who oppose the harvesting of organs. Today, procurement practices must meet stringent ethical criteria. This means that the life-saving team is kept separate from the organ-procuring team. The public needs to be informed of these safeguards, which will put unfounded fears to rest.
- Some fear that presumed consent means procurers might act too quickly in removing organs upon the declaration of death. This would be morally objectionable because it may harm members of the patient’s family if they disagree with the medical criteria for death. If there is disagreement with the medical opinion physicians should respect that and give the family time to accept that the person is dead according to well-established and contemporary criteria.

I can continue to list technical objections and technical solutions, but there is a way to resolve all such concerns. Presumed consent is designed to protect individual auton-



omy. Proponents of presumed consent need to show the public that they are not "organ vultures" but instead are trying to respect human freedom and dignity while trying to meet the increasing demand for organs.

Conclusion

Altruistic voluntarism is not providing enough donor organs. Although most people appreciate the miracle of transplantation, many are reluctant to sign the donor cards that make the miracle possible. The opting-in policy currently in play fails to make enough organs available, fails to save the lives of some ESO patients and fails to respect the autonomy of donors and nondonors alike. We need a radical change in policy that is both potentially effective and morally and socially desirable.

A presumed-consent policy can significantly increase the supply of organs while at the same time supporting the autonomous wishes of the majority concerning the use of body parts after death. Presumed consent would protect individual autonomy more than our current system, without being insensitive to the wishes of the next of kin. We will be making a great moral mistake if we fail to adopt an ethically acceptable policy of presumed consent that would help save many lives.

I will end by quoting David Longmore: "We either preserve the ancient laws that guarantee the inviolability of the dead, and the present rights of the next of kin, or we can rewrite those laws in favour of the living."¹⁴

References

1. Turcotte JG. Supply, demand and ethics of organ procurement: the medical perspective. *Transplant Proc* 1992;24(5):2140-2.
2. Eley JA. *Organ procurement and transplantation: mandating appropriate legislation*. Edmonton: University of Alberta; 1992.
3. Dukeminier J Jr, Sanders D. Organ transplantation: a proposal for routine salvaging of cadaver organs. *N Engl J Med* 1968;279:413-9.
4. Guttman RD, Guttman A. Organ transplantation: duty reconsidered. *Transplant Proc* 1992;24(5):2179-80.
5. Evans RW. Need, demand and supply in organ transplantation. *Transplant Proc* 1992;24(5):2152-4.
6. Roels L, Vanreenterghem Y, Waer M, Christiaens MR, Gruwez J, Michielsens P. Three years of experience with a 'presumed consent' legislation in Belgium: its impact on multi-organ donation in comparison with other European countries. The Leuven Collaborative Group for Transplantation. *Transplant Proc* 1991;23(1Pt2):903-4.
7. Gnant MF, Wamser P, Goetzinger P, Sautner T, Steininger R, Muehlbacher F. The impact of the presumed consent law and a decentralized organ procurement system on organ donation: quadruplication in the number of organ donors. *Transplant Proc* 1991;23(5):2685-6.
8. Peter DA. Protecting autonomy in organ procurement procedures: some overlooked issues. *Milbank Q* 1986;64(2):241-70.
9. Cox M. *Human transplantation in Canada: the problems — the challenge*. Edmonton: Human Parts Banks of Canada; 1978.
10. Hessing RJ. The social dilemma of organ donation: Opting in or opting out — is that the question? In: Shanteau J, Harris RJ, editors. *Organ donation and transplantation: psychological and behavioral factors*. Washington: American Psychological Association; 1990. p. 72-82.
11. Teo B. Organs for transplantation. The Singapore experience. *Hastings Cent Rep* 1991;21(6):10-3.
12. Sadler BL. Presumed consent to organ transplantation: a different perspective. *Transplant Proc* 1992;24(5):2173-4.
13. Cohen C. The case for presumed consent to transplant human organs after death. *Transplant Proc* 1992;24(5):2168-72.
14. Kennedy I. The donation and transplantation of kidneys: Should the law be changed? *J Med Ethics* 1979;5:13-21.

CMA/American Medical Association 1998 International Conference on Physician Health

MANAGING OUR OWN CARE: SURVIVING THE HEALTH CARE REVOLUTION

The Empress Hotel & Victoria Conference Centre
Victoria, BC
April 29 - May 2, 1998

This conference on physician health brings a broad, proactive, preventive approach to reduce all types of physician health problems and to offer assistance before there is actual impairment.

Presentations will examine well-being, impairment, disability, treatment and education. Specific topics include:

- coping with changing economic or practice circumstances
- stress and depression
- physician self-care
- updates on clinical areas (depression, pharmacotherapy, etc.)
- physical illness and disability
- violence directed at physicians

For registration information contact:

International Conference on Physician Health
American Medical Association
515 N State St., Chicago, IL, 60610
tel 312 464-5073; fax 312 464-5826
elaine_tejcek@ama-assn.org